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14. ABSTRACT The objective of this project is to develop an NF1-specific health-related quality of life (HRQL) instrument for use with pediatric patients. Semi-structured interviews with children with NF1, their parents, and teachers were used to derive important domains and item content, and the first-generation instrument was developed. This instrument has undergone an initial examination of its psychometric properties and the content was revised accordingly. Following this initial field trial, the second generation instrument will be tested administered in a battery of measures to furthers assess its reliability and validity as well as its applicability in a clinical trials setting. At the conclusion of this third year, we have completed all interviews, transcribed all interviews, and reviewed them for content. This content review was then used to develop the first-generation instrument. The instrument was completed by 83 children with NF1 and 83 parents of children with NF1. The resulting responses have been analyzed for internal consistency and feasibility. The instrument demonstrated acceptable internal consistency (coefficient <i>alpha</i>) and was not perceived as either difficult or upsetting to complete. The final task of this project focuses on the test-retest reliability and validity of the instrument. Children with NF1 and their parents will complete the NF1-specific measure, in addition to parent- and self-report measures of behavior, functioning, and generic health-related quality of life.					
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Table of Contents

Introduction.....	4
Body.....	4
Key Research Accomplishments.....	5
Reportable Outcomes.....	5
Conclusions.....	None
References.....	None
Appendices.....	5

1. INTRODUCTION

The objective of this project is to develop an NF1-specific health-related quality of life (HRQL) instrument for pediatric patients and their parents. Semi-structured interviews with children with NF1, their parents, and teachers yielded relevant domains and content that were used to develop the first-generation instrument.

This first-generation instrument was field tested for psychometric properties and understandability and then revised. The revised instrument will be completed by a group of children and their parents to test its validity and sensitivity to change in clinical status. It is our hypothesis that the addition of this disease-specific measure will significantly improve the descriptiveness and quantification of the impact of NF1 and its treatment on children's lives.

2. BODY

The original Statement of Work identified the following tasks:

Task 1: Identify domains and items to reflect important aspects of HRQL (COMPLETED)

-
- Complete review of literature to gather previously identified HRQL topics
 - Develop standardized interviews for patients, parents, teachers, and health care professionals
 - Pilot interviews and modify as needed
 - Conduct interviews of patients, parents, teachers and health care professionals
 - Transcribe interviews, review for functioning areas impacted by NF1

Task 2: Administer preliminary items to sample of NF1 patients and parents and use item analysis methods to construct preliminary HRQL instrument. (COMPLETED)

-
- Recruit NF1 participants and parents
 - Mail out questionnaires for completion and return
 - Enter and analyze data
 - Produce final NF1-specific instrument for studies in subsequent tasks

Task 3: Conduct reliability, validity and responsivity studies for NF1 instrument (IN PROGRESS)

Additionally, although not stated in the original Statement of Work, we were required to gain approval from both the Army/Department of Defense Human Subjects Review Board and our local Institutional Review Board prior to recruiting participants. Because of the manner in which the projects were proposed, and the reliance on material/questionnaires developed at each stage, it was necessary to submit separate Human Subjects protocols for each of the 3 projects (interviews, first-generation validation, and final version validation).

Status of Work. As noted in prior reports, Task 1 has been completed. At the time of the last Annual Report, we had largely completed all of the tasks in #2. The resulting work product from Task 2 was an NF1-specific HRQL instrument, which demonstrates acceptable psychometric properties, including internal validity. Since August 2005, we have completed revisions to produce the final NF-1 specific instrument (primarily formatting and readability changes) which we are using in Task 3. Additionally, data files were verified for accuracy and completeness and the preliminary findings were confirmed and finalized.

In regard to Task 3, which is currently in progress, we have received initial approval for the project from the West Virginia University Institutional Review Board for the Protection of Human Subjects. That

information was subsequently reviewed by the Department of Defense Human Subjects Review Board and returned to us with suggested revisions. Those revisions were taken through the review process at WVU again, and we are now awaiting final approval of the documents and protocol from the Department of Defense.

3. KEY RESEARCH ACCOMPLISHMENTS

1. The primary accomplishment from the research thus far has been the development of HRQL instrument for youth with NF1 and their parents.

4. REPORTABLE OUTCOMES AND CONCLUSIONS

We have demonstrated the feasibility of working with professionals and children with NF1 and their parents to develop an instrument assessing the health-related quality of life of these children. The resulting measure has demonstrated acceptable psychometric properties in terms of its descriptiveness and internal validity. Importantly from a practical standpoint, respondents did not perceive the instrument as either burdensome or distressing, and reported that it accurately reflected HRQL.

5. REFERENCES

None

6. APPENDICES

The most current versions of the NF1 instruments for parents and for children are included in the Appendix.

General Health				
1. In general, I would say that my health is:				
1	2	3	4	5
Poor				Excellent
2. Compared to this time last year, I would say my health is:				
1	2	3	4	5
Much Worse				Much Better
3. I get sick more easily than other kids:				
1	2	3	4	5
Yes, Definitely				No, not at all

In the past week, have you:

	Always		Sometimes		Never
4. Had difficulty falling asleep or staying asleep?	1	2	3	4	5
5. Had bad dreams or nightmares?	1	2	3	4	5
6. Been less hungry than usual?	1	2	3	4	5
7. Been more hungry than usual?	1	2	3	4	5

If you received help, please circle the question numbers on this page for which you needed help.

Pain**In the past week, have you:**

	Always		Sometimes		Never
8. Hurt a lot?	1	2	3	4	5
9. Has muscle pains or aches?	1	2	3	4	5
10. Had headaches?	1	2	3	4	5
11. Had stomachaches?	1	2	3	4	5
12. Had pain in your bones or joints?	1	2	3	4	5
13. Had neurofibromas or other areas on your body that hurt to touch?	1	2	3	4	5

14. Compared to other people my age, the amount of pain I have is	Much More		About the Same		Much Less
	1	2	3	4	5
15. Pain keeps me from doing the things that I want to do or need to do	Very True		Somewhat		Not at all
	1	2	3	4	5

Who helped you fill out this page? (Circle One) Mother Father No One Other_____

If you received help, please circle the question numbers on this page for which you needed help.

Understanding

In the past week, were you:

16. Bothered that you didn't know enough about NF-1?

1 2 3 4 5
A lot Some Not at all

17. Frustrated about having NF-1?

1 2 3 4 5
A lot Some Not at all

Sensation

In the past week, have you:

	Always		Sometimes		Never
18. Had difficulty hearing others when they talk? Check here if you wear a hearing aid _____	1	2	3	4	5
19. Had trouble seeing well? Check here if you wear glasses or contacts _____	1	2	3	4	5
20. Had trouble feeling the things you touch?	1	2	3	4	5

Who helped you fill out this page? (Circle One) Mother Father No One Other_____

If you received help, please circle the question numbers on this page for which you needed help.

Symptoms - 1**In the past week, have you:**

	Always		Sometimes		Never
21. Felt sick to your stomach?	1	2	3	4	5
22. Had a headache?	1	2	3	4	5
23. Had a stomachache?	1	2	3	4	5
24. Had a hard time breathing?	1	2	3	4	5
25. Felt dizzy or like you might faint?	1	2	3	4	5
26. Felt weak?	1	2	3	4	5
27. Felt tired or fatigued?	1	2	3	4	5
28. Had a hard time swallowing?	1	2	3	4	5
29. Had a hard time keeping your balance?	1	2	3	4	5
30. Had a difficulty tying shoes, using scissors, holding a pencil?	1	2	3	4	5
31. Been clumsy?	1	2	3	4	5
32. Had a hard time riding a bike, running, or catching a ball?	1	2	3	4	5

Who helped you fill out this page? (Circle One) Mother Father No One Other _____

If you received help, please circle the question numbers on this page for which you needed help.

Psychological and Behavioral - 1**In the past week, have you:**

	Always		Sometimes		Never
33. Felt cranky or irritable?	1	2	3	4	5
34. Worried?	1	2	3	4	5
35. Felt anxious?	1	2	3	4	5
36. Gotten easily frustrated?	1	2	3	4	5
37. Gotten in trouble because of your behavior at school?	1	2	3	4	5
38. Gotten in trouble because of your behavior at home?	1	2	3	4	5
39. Felt afraid or scared?	1	2	3	4	5
40. Felt sad, down, or depressed?	1	2	3	4	5
41. Felt angry?	1	2	3	4	5
42. Worried about what might happen to you?	1	2	3	4	5
43. Felt like crying?	1	2	3	4	5
44. Felt lonely?	1	2	3	4	5
45. Felt cheerful?	1	2	3	4	5

Who helped you fill out this page? (Circle One) Mother Father No One Other_____

If you received help, please circle the question numbers on this page for which you needed help.

Psychological and Behavioral - 2**In the past week, have you:**

	Always		Sometimes		Never
46. Felt confident about yourself?	1	2	3	4	5
47. Enjoyed the things you do?	1	2	3	4	5
48. Had fun?	1	2	3	4	5
49. Felt jittery or restless?	1	2	3	4	5
50. Argued?	1	2	3	4	5
51. Wanted to be alone?	1	2	3	4	5
52. Had mood swings?	1	2	3	4	5
53. Not done what your parent or teacher asked?	1	2	3	4	5
54. Had anxiety or panic attacks?	1	2	3	4	5
55. Hit or kicked someone?	1	2	3	4	5
56. Heard voices that weren't there?	1	2	3	4	5
57. Compared to other children your age, would you say your behavior is:					
1 2 3 4 5					
Much Worse Ok Much Better					

Who helped you fill out this page? (Circle One) Mother Father No One Other_____

If you received help, please circle the question numbers on this page for which you needed help.

School and Cognition -1

In the past week, have you:

	Always		Sometimes		Never
58. Missed school because of your health? Check here if school was on vacation ____	1	2	3	4	5
59. Been bothered because you missed school? Check here if you haven't missed any school ____	1	2	3	4	5
60. Missed school to go to the doctor or hospital?	1	2	3	4	5
61. Had difficulty solving math problems?	1	2	3	4	5
62. Had trouble writing papers or reports?	1	2	3	4	5
63. Had trouble following or understanding directions?	1	2	3	4	5
64. Had difficulty remembering what you read?	1	2	3	4	5
65. Had trouble reading?	1	2	3	4	5
66. Forgotten things?	1	2	3	4	5
67. Had trouble keeping up with your schoolwork?	1	2	3	4	5

Who helped you fill out this page? (Circle One) Mother Father No One Other_____

If you received help, please circle the question numbers on this page for which you needed help.

School and Cognition -2**In the past week, have you:**

	Always		Sometimes		Never
68. Had trouble turning your schoolwork in on time?	1	2	3	4	5
69. Had difficulty paying attention and concentrating in class?	1	2	3	4	5
70. Had trouble writing neatly?	1	2	3	4	5
71. Had a hard time sitting still in class?	1	2	3	4	5
72. Had trouble organizing your work or things?	1	2	3	4	5
73. Had trouble spelling?	1	2	3	4	5

In the past week:

74. How would you rate your ability to do your schoolwork?

1 2 3 4 5
Poor Ok Excellent

Who helped you fill out this page? (Circle One) Mother Father No One Other_____

If you received help, please circle the question numbers on this page for which you needed help.

Social Relations**In the past week, have you:**

	Always		Sometimes		Never
75. Had trouble getting along with other kids?	1	2	3	4	5
76. Helped others?	1	2	3	4	5
77. Preferred to be alone?	1	2	3	4	5
78. Preferred quiet activities?	1	2	3	4	5
79. Avoided doing things with other kids?	1	2	3	4	5
80. Felt bothered because you couldn't do the activities you like?	1	2	3	4	5
81. Felt like other kids didn't want to do things with you?	1	2	3	4	5
82. Felt like other kids didn't want to be your friend?	1	2	3	4	5

	Poor		Ok		Excellent
83. How would you rate your family's ability to get along with each other?	1	2	3	4	5
84. How would you rate your ability to get along with other kids?	1	2	3	4	5

Who helped you fill out this page? (Circle One) Mother Father No One Other_____

If you received help, please circle the question numbers on this page for which you needed help.

Appearance**In the past week, have you:**

	Always		Sometimes		Never
85. Been teased about how you look?	1	2	3	4	5
86. Felt bad about how you look?	1	2	3	4	5
87. Worried about how you look?	1	2	3	4	5
88. Been teased about your height/weight?	1	2	3	4	5
89. Avoided doing things with others because of how you look?	1	2	3	4	5
90. Done things to hide part of your body because of how it looks?	1	2	3	4	5
91. Noticed people staring at you?	1	2	3	4	5
92. Heard strangers make rude comments about you?	1	2	3	4	5
93. Worried about other people teasing you?	1	2	3	4	5

94. I am satisfied with the way I look	1	2	3	4	5
	Not at all		Somewhat		Very much

Who helped you fill out this page? (Circle One) Mother Father No One Other _____

If you received help, please circle the question numbers on this page for which you needed help.

Speech and Language**In the past week, have:**

	Always		Sometimes		Never
95. Other people had a hard time understanding you when you talk?	1	2	3	4	5
96. You had a hard time understanding what other people say to you?	1	2	3	4	5

Global Ratings

97. How well did the questions in this survey describe your quality of life?

Poor		Somewhat		Excellent
1	2	3	4	5

98. How would you rate your overall quality of life?

Poor		Ok		Excellent
1	2	3	4	5

99. How difficult was it to complete this survey?

Very		Somewhat		Not at all
1	2	3	4	5

100. How upsetting was it to complete this survey?

1	2	3	4	5
---	---	---	---	---

Who helped you fill out this page? (Circle One) Mother Father No One Other _____

If you received help, please circle the question numbers on this page for which you needed help.

Thank you!

Please Put Your Completed Survey in the Stamped, Addressed Envelope and Drop in the Mail!

General Health

1. In general, I would say that my child's health is:	1	2	3	4	5
	Poor			Excellent	
2. Compared to this time last year, I would say my child's health is:	1	2	3	4	5
	Much Worse			Much Better	
3. My child gets sick more easily than other kids:	1	2	3	4	5
	Yes, Definitely			No, not at all	

Appetite and Sleep

In the past week, has your child:

	Always	Sometimes			Never
4. Had difficulty falling asleep or staying asleep?	1	2	3	4	5
5. Had bad dreams or nightmares?	1	2	3	4	5
6. Been less hungry than usual?	1	2	3	4	5
7. Been more hungry than usual?	1	2	3	4	5

Pain

In the past week, has your child:

	Always		Sometimes		Never
8. Hurt a lot?	1	2	3	4	5
9. Has muscle pains or aches?	1	2	3	4	5
10. Had headaches?	1	2	3	4	5
11. Had stomachaches?	1	2	3	4	5
12. Had pain in his/her bones or joints?	1	2	3	4	5
13. Had neurofibromas or other areas on his/her body that hurt to touch?	1	2	3	4	5

	Much More	About the Same			Much Less
14. Compared to other people my child's age, the amount of pain my child has is	1	2	3	4	5
	Very True		Somewhat		Not at all
15. Pain keeps my child from doing the things that s/he wants to do or needs to do	1	2	3	4	5

Understanding

In the past week, was your child:

	A lot		Some		Not at all
16. Bothered that s/he didn't know enough about NF-1?	1	2	3	4	5
17. Frustrated about having NF-1?	1	2	3	4	5

Sensation

In the past week, has your child:

	Always		Sometimes		Never
18. Had difficulty hearing others when they talk?	1	2	3	4	5
Check here if s/he wears a hearing aid _____					
19. Had trouble seeing well?	1	2	3	4	5
Check here if s/he wears glasses or contacts _____					
20. Had trouble feeling the things s/he touches?	1	2	3	4	5

Symptoms - 1

In the past week, has your child:

	Always		Sometimes		Never
21. Felt sick to his/her stomach?	1	2	3	4	5
22. Had a headache?	1	2	3	4	5
23. Had a stomachache?	1	2	3	4	5
24. Had a hard time breathing?	1	2	3	4	5
25. Felt dizzy or like s/he might faint?	1	2	3	4	5
26. Felt weak?	1	2	3	4	5
27. Felt tired or fatigued?	1	2	3	4	5
28. Had a hard time swallowing?	1	2	3	4	5
29. Had a hard time keeping his/her balance?	1	2	3	4	5

Symptoms - 2

In the past week, has your child:

	Always		Sometimes		Never
30. Had a difficulty tying shoes, using scissors, holding a pencil?	1	2	3	4	5
31. Been clumsy?	1	2	3	4	5
32. Had a hard time riding a bike, running, or catching a ball?	1	2	3	4	5

Psychological and Behavioral - 1

In the past week, has your child:

	Always		Sometimes		Never
33. Felt cranky or irritable?	1	2	3	4	5
34. Worried?	1	2	3	4	5
35. Felt anxious?	1	2	3	4	5
36. Gotten easily frustrated?	1	2	3	4	5
37. Gotten in trouble because of his/her behavior at school?	1	2	3	4	5
38. Gotten in trouble because of his/her behavior at home?	1	2	3	4	5
39. Felt afraid or scared?	1	2	3	4	5
40. Felt sad, down, or depressed?	1	2	3	4	5
41. Felt angry?	1	2	3	4	5
42. Worried about what might happen to him/her?	1	2	3	4	5

Psychological and Behavioral - 2

In the past week, has your child:

	Always		Sometimes		Never
43. Felt like crying?	1	2	3	4	5
44. Felt lonely?	1	2	3	4	5
45. Felt cheerful?	1	2	3	4	5
46. Felt confident about him/herself?	1	2	3	4	5
47. Enjoyed the things s/he does?	1	2	3	4	5
48. Had fun?	1	2	3	4	5
49. Felt jittery or restless?	1	2	3	4	5
50. Argued?	1	2	3	4	5
51. Wanted to be alone?	1	2	3	4	5
52. Had mood swings?	1	2	3	4	5
53. Not done what his/her parent or teacher asked?	1	2	3	4	5
54. Had anxiety or panic attacks?	1	2	3	4	5
55. Hit or kicked someone?	1	2	3	4	5
56. Heard voices that weren't there?	1	2	3	4	5

	Much Worse		Ok	Much Better	
57. Compared to other children your child's age, would you say your child's behavior is:	1	2	3	4	5

School and Cognition -1

In the past week, has your child:

	Always		Sometimes		Never
58. Missed school because of his/her health?	1	2	3	4	5
Check here if school was on vacation ____					
59. Been bothered because s/he missed school?	1	2	3	4	5
Check here if your child hasn't missed any school ____					
60. Missed school to go to the doctor or hospital?	1	2	3	4	5
61. Had difficulty solving math problems?	1	2	3	4	5
62. Had trouble writing papers or reports?	1	2	3	4	5
63. Had trouble following or understanding directions?	1	2	3	4	5
64. Had difficulty remembering what s/he read?	1	2	3	4	5
65. Had trouble reading?	1	2	3	4	5
66. Forgotten things?	1	2	3	4	5
67. Had trouble keeping up with schoolwork?	1	2	3	4	5
68. Had trouble turning schoolwork in on time?	1	2	3	4	5

School and Cognition -2

In the past week, has your child:

	Always		Sometimes		Never
69. Had difficulty paying attention and concentrating in class?	1	2	3	4	5
70. Had trouble writing neatly?	1	2	3	4	5
71. Had a hard time sitting still in class?	1	2	3	4	5
72. Had trouble organizing work or things?	1	2	3	4	5
73. Had trouble spelling?	1	2	3	4	5

In the past week;

	Poor		Ok		Excellent
74. How would you rate your child's ability to do schoolwork?	1	2	3	4	5

Social Relations - 1

In the past week, has your child:

	Always		Sometimes		Never
75. Had trouble getting along with other kids?	1	2	3	4	5
76. Helped others?	1	2	3	4	5
77. Preferred to be alone?	1	2	3	4	5
78. Preferred quiet activities?	1	2	3	4	5
79. Avoided doing things with other kids?	1	2	3	4	5

Social Relations - 2

In the past week, has your child:

	Always		Sometimes		Never
80. Felt bothered because s/he couldn't do the activities they like?	1	2	3	4	5
81. Felt like other kids didn't want to do things with them	1	2	3	4	5
82. Felt like other kids didn't want to be his/her friend?	1	2	3	4	5
	Poor		Ok		Excellent
83. How would you rate your family's ability to get along with each other?	1	2	3	4	5
84. How would you rate your child's ability to get along with other kids?	1	2	3	4	5

Appearance - 1

In the past week, has your child:

	Always		Sometimes		Never
85. Been teased about how they look?	1	2	3	4	5
86. Felt bad about his/her appearance?	1	2	3	4	5
87. Worried about their looks?	1	2	3	4	5
88. Been teased about size?	1	2	3	4	5
89. Avoided doing things with others because of how s/he looks?	1	2	3	4	5

Appearance - 2

In the past week, has your child:

	Always		Sometimes		Never
90. Done things to hide part of their body because of how it looks?	1	2	3	4	5
91. Noticed people staring at them?	1	2	3	4	5
92. Heard strangers make rude comments about them?	1	2	3	4	5
93. Worried about other people teasing them?	1	2	3	4	5
	Not at all		Somewhat		Very much
94. My child is satisfied with his/her looks	1	2	3	4	5

Speech and Language

In the past week, have:

	Always		Sometimes		Never
95. Other people had a hard time understanding our child when s/he talks?	1	2	3	4	5
96. My child had a hard time understanding what other people said to them?	1	2	3	4	5

Global Ratings

	Poor		OK		Excellent
97. How would you rate your child's overall quality of life?	1	2	3	4	5

	Very		Somewhat		Not at all
98. How difficult was it to complete this survey?	1	2	3	4	5
How upsetting was it to complete this survey?	1	2	3	4	5

	Poor		Somewhat		Excellent
99. How well did the questions in this survey describe your child's quality of life?	1	2	3	4	5
100. What other things would you like to see added that might better describe your child?					

Please Put your Completed Survey in the Stamped, Addressed Envelope and Drop in the Mail! Thank you!